

# Why there is no MCS advocacy organization in the United States

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**The United States has no organization focused on advocating for the people with multiple chemical sensitivity/environmental illness. Here is the history and explanation.**

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People with MCS have for more than sixty years been ignored, ridiculed, and discriminated against by the medical system, government agencies, the media, and others. There has never been any funding for serious research to answer the many open questions of why people get sick, how the illness works, and how to treat it effectively.

Other groups with ignored illnesses organized, such as for AIDS, black lung disease (coal miners), brown lung disease (cotton mill workers), autism, Alzheimer's and more.

Surgeon Sherman Nuland wrote about advocacy for Alzheimer's research (Nuland 1995):

*As a result of all the coordinated efforts, the Alzheimer's research budget in the United States in 1987 was eight hundred times what it had been only ten years earlier.*

A retired cotton mill worker from South Carolina once stated about brown lung disease (Judkins 1983):

*Lawyers shrug, legislators throw up their arms, industrial commissions duck, and the industry tries to pretend there is no problem. Well, we are living proof.*

Sounds very familiar to people with MCS today.

Other groups have demanded to be accepted and not be discriminated against. That includes civil rights for Blacks, the women's liberation of the sixties and seventies, and the LGBT+ campaigns that ran for several decades.

## **The first opportunity**

The issue of civil rights for people with MCS gathered steam in the late 1980s and culminated around the year 1990, when there was suddenly a lot of sympathetic coverage in the media across the United States. The Federal agency Housing and Urban Development (which provides low-cost housing for the disabled) accepted MCS sufferers as deserving accommodation.

In San Francisco MCS demonstrators were able to shut down a blatantly biased medical conference. President George H. W. Bush invited three representatives from the MCS community to attend the outdoor ceremony where he signed the Americans with Disabilities Act into law. A ten-year-old boy with MCS testified before a Congress committee on how pesticides had ruined his health (EI Wellspring 2023).

But the MCS activists were not well organized, and there were many other difficulties. When they faced stiff organized opposition, they were not able to persevere. They lost traction, the momentum stopped, the media changed sides, and the whole thing fell apart within a few years. The movement never recovered.

The story of how the opposition was able to win is told elsewhere (EI Wellspring 2023). Here we look at the difficulties there were, and still are, creating an effective MCS advocacy organization.

## **The need to get organized**

Individuals can do very little, unless they are very rich. Politicians, high-level administrators, researchers, and other decisionmakers do not waste their time on individuals; they want to talk to people who represent a group of people. The larger group the better, especially if it has money to spend.

Organizations also have the contacts and resources to distribute information, including to their members. And when needed, they are able to contact sympathizers and ask them to show up in person for a show of support when a decisionmaker needs convincing.

A well-run organization also cultivates relationships with other grass-roots organizations for mutual support when needed.

A hundred people showing up in person to protest something is much more impressive to a decisionmaker than ten thousand signatures on an online petition.

## The MCS organizations

An obvious path to get organized was for an existing organization to take on the task. Around 1990 there were dozens of small local groups that were essentially social clubs. Then there were a few that had a nationwide audience for their newsletters.

The National Center for Environmental Health Strategies was started in the 1980s by Mary Lamielle in New Jersey.

The Chemical Injury Information Network (CIIN) was started in 1990 by Cynthia Wilson and her husband John Wilson. They focused on publishing their monthly newsletter *Our Toxic Times*.

Alison Johnson in Maine focused on doing surveys in the MCS community and disseminate information through her MCS Information Exchange, besides sending books to politicians.

There was also the MCS Resources and Referral (MCSRR) in Baltimore.

These outfits were essentially clearinghouses for information. They consisted of just one or two people.

The largest organization was the Human Ecology Action League (HEAL). It started in 1977 in Chicago; a decade later it moved to Atlanta where it had a real business office and a handful of active members. Despite the word “action” in its name, it did no advocacy work. It focused on getting along with the toxic world, not changing it.

HEAL put out a quarterly magazine, *The Human Ecologist*, and worked on growing a network of local affiliates. In 1986 HEAL had 72 chapters in 24 states (HE 1986).

The local chapters were social clubs where people with MCS could have the freedom of being among others who understood what living with MCS was like, and not constantly having to dodge other people’s cigarettes and cologne. People banded together organizing organic foods and other non-toxic essentials, which were not readily available in those years. And they held picnics and meetings with speakers.

Many of the local chapters had their own newsletters, since the internet was not yet available. The HEAL organization had the infrastructure in place to do advocacy work, but it didn't and the local chapters were strongly discouraged from doing any on their own. This was apparently due to the HEAL leadership consisting of mostly older conservative women who considered activism undignified and repulsive. When Mary Lamielle was on the HEAL board, she suggested that the activist Susan Molloy be invited to join, but that was vigorously voted down.

In California there was the Environmental Health Association (EHA) which had its own newsletter called *The Reactor* (later renamed *The New Reactor*), that was edited by Susan Molloy. The EHA had a handful of chapters around the state, and was itself an affiliate of the national HEAL organization.

Since the EHA was barred from doing activist work because it was affiliated with HEAL, it spawned the Environmental Health Network (EHN) in the late 1980s. EHN was spearheaded by Susan Molloy and based in Marin County just north of San Francisco.

The EHN became one of just a few MCS organizations to do real activist work to improve the lives of people with the disease. In the early 1990s they mounted some public protests in San Francisco, including when actor Elizabeth Taylor unveiled her new signature fragrance and when the fragrance industry held their annual conference there. They received sympathetic coverage by the local print media, and the local affiliate of PBS made a splendid television program that featured one of the protests.

The San Francisco Bay area was a hotbed of all sorts of progressive activism in the 1960s and 1970s, and there was still some of that spirit left. It is no wonder the EHN was created there.

Unfortunately, the EHN never grew beyond San Francisco and within a few years it fizzled out. In the following we'll look at the factors that caused the organization's rapid decline.

The only other MCS activist group we've found was based in Southwest Florida, around St. Petersburg and Sarasota. In the 1980s it focused on pesticide issues and was able to get the state government to create a registry of people who must be notified before pesticides are sprayed near their homes. It applied only to commercial pesticide and lawn care companies (Osborn 2009).

Otherwise there were only a few people who worked on local projects, such as the folks in Wimberley, Texas, protesting toxic renovations of their local school.

### **Disability barriers**

Having a disability makes activist work more difficult and deters people from doing it. There are not many people in wheelchairs participating in demonstrations.

MCS is a strong deterrent, as people often don't feel well, and going out in public is hazardous.

People with mild MCS can function so well in society that they are less motivated to push for better acceptance. And many want to keep their condition secret due to the stigma associated with MCS.

Those with mid-level MCS may be more motivated, but may also be struggling to hold on to their jobs, so they have little extra energy. And they too tend to stay closeted.

That leaves the severe cases, who are the most limited in what they can do. There are good reasons why they no longer work. They are also a small minority of the overall MCS population. These were the people who mounted the EHN protests in San Francisco, and they largely had to do them outdoors, as they would get sick inside buildings. For some events they had to ask for help from other groups, especially the AIDS activists.

Many of the tactics used by other movements are not feasible. All it takes to get rid of MCS protestors is threatening them with a spraycan of pesticides or a so-called "air freshener."

Healthy family members, the spouses and adult children of the sick, did not step in and become activists. That happened with Autism Speaks, but not for the MCS cause.

### **Harassment**

People with MCS are vulnerable to harassments that the police is likely to consider harmless and trivial.

In her memoir, Rita Osborn talks about her activist work in Florida and that she herself and others were harassed in various ways, including by people who

sprayed pesticides around their houses at night. This got Rita to greatly limit her activist work (Osborn 2009).

Very recently, a Canadian activist was harassed by someone who contacted her disability case manager and said she was a malingerer who should not receive disability benefits.

Such harassment is rare, but the possibility may deter some people from activist work.

There is also the fear that activism can alienate regular people who otherwise tolerate the people with MCS. That it could lead to random harassment. This might have been a reason why HEAL opposed any activism.

### **A young person's game**

When people start doing activist work, they are usually in their twenties. Then they may continue for decades, but it is seldom people start later in life. Older people are simply less comfortable with walking in protest marches, etc. Some of that sentiment may be caused by the media, which tends to ignore peaceful protests and only cover the few that are either violent or spectacular.

MCS usually first hits people when they are in their thirties or forties, and thus already past the typical age of starting activism.

Once sick with MCS, it takes some years to find out what is going on, as the doctors tend to brush it off. It takes time to figure out how to live with the illness and reduce the exposures, so they feel better and can look beyond their immediate needs.

Most of the prominent activists for the MCS cause either got sick early, or they had already been involved in other kinds of activist work before they got sick.

### **Scattered constituency**

A movement that appeals to educated young people can quickly and cheaply reach a lot of potential supporters on a university campus. And they do not have to be transported from afar if doing a public protest. There is also the dynamic that some students can convince more reluctant ones to come along.

In contrast, people with MCS are scattered, especially since the severe cases tend to move away from densely populated areas. Such atomized constituencies are a lot harder to reach, motivate, and organize.

## **Attrition**

The San Francisco MCS community lost most of its active people. Ten moved away to the clean dry air of Arizona and New Mexico. Five moved to Hawaii, also to find clean air. This scattered them so there was no longer physical contact between them and they were far away from major cities, which made it more difficult to be heard.

A couple continued to do activist work in their new locations. Ann McCampbell got the New Mexico government to consider accommodating people with MCS in 1996, though the effort was quickly defeated when droves of industry lobbyists descended on Santa Fe (EI Wellspring 2023).

Susan Molloy settled in the high desert of Arizona near the town of Snowflake. She was able to attract dozens of other people with MCS to the area, and get housing built that was suitable for them. This included four houses for low-income disabled people, which was funded with government money.

Susan Molloy compensated for her remote location by traveling a few times a year, such as to national disability conferences where she tried to convince people with more “accepted” disabilities to show solidarity with the people with MCS. Travel on airplanes was hard; sometimes the flight attendants practically had to carry her off the plane after it landed.

It takes a certain amount of initiative to pull up stakes and move to another state, while people with less initiative tend to stay put. This contributed to the stagnation of the San Francisco group.

It wasn't all the leaders who left San Francisco, Julia Kendall and Barbara Wilkie stayed behind. Julia sued American Airlines for exposing her to pesticides on a flight and organized protests against fragrances, which were even mentioned in the *New York Post*. Both Julia and Barbara died of leukemia in the late 1990s, and had to stop their activism before that.

By the late 1990s there were virtually no active people in San Francisco. If the local groups had not lost those people they might eventually have turned into a national force.

There were also people from other parts of the country who ended up living remotely. A few did what they could from there.

The Wilsons settled in small-town Montana, where they created CIIN and published *Our Toxic Times*.

Cindy Duehring was confined to her home in rural North Dakota. She wrote more than a hundred well-researched articles for *Our Toxic Times*, and produced the magazine *Informed Consent*, which was aimed at a wider audience, but she died at the age of 35. The cause of death was apparently pesticide drift.

### **No public crisis**

Many movements have languished until some sort of public crisis made the injustice obvious. The national media finds it newsworthy, the movement gets new members and donations, which builds momentum that attracts yet more support. People want to join a winning team.

This happened to the civil rights movement in the early 1960s when white police officers savagely beat up peaceful Black marchers crossing the Edmund Pettus bridge in Selma, Alabama. Another such event was the Montgomery bus boycott when Rosa Parks was jailed for refusing to give up her seat for a white traveler and move to the back of the segregated bus.

The LGBT+ community was deeply demoralized in the 1960s. That changed when a spontaneous riot erupted against police brutality at the Stonewall Inn bar in New York. It showed they were not powerless after all.

The community got really organized during the AIDS crisis in the 1980s, when it became clear that the American health authorities just sat and watched thousands of people die without lifting a finger to help.

The women's liberation movement got a lot of media attention and new members, when radical feminists staged a big protest at the sexist Miss America pageant in Atlantic City in 1968.

Users of wheelchairs were able to get a law implemented in 1977 that gave them access to schools and higher education. They were ignored until they occupied a Federal building in San Francisco for three weeks.

More recently, the Black Lives Matter movement got going when a white police officer choked a helpless Black man to death. There had been several other killings, but this one was caught on video.

The MCS community has not had any such events that could pull people together to do something about the many injustices. The media interest has mostly been focused on producing sensational freak shows instead.

## **Demoralized**

A movement that produces results will attract more members and donations, which makes the movement stronger and able to produce more successes and build up a momentum.

In the early 1990s MCS activists saw some incremental gains, acceptance in the media, and sympathy from the public. Then the chemical and tobacco industries unleashed their public relations and political muscle in a campaign to discredit people with MCS (EI Wellspring 2023).

Within just a few years MCS became widely believed to be a psychiatric illness, with the sufferers not worthy of any respect. The media became hostile, the activists faced solid brick walls wherever they went. This greatly demoralized a lot of people so they stopped being active.

## **Lack of public support**

It helps the morale of the activists if they know the public has sympathy for their cause, or at least does not oppose it.

The public can easily be sympathetic to people who fight injustice that is portrayed as such on television screens and other media. The sympathies become much more tenuous if the public sees itself impacted by the issue. Past examples were uneasiness about allowing gay people to be school teachers; men who found it ridiculous that women demanded to be treated as adults; Southerners who could not accept the end of segregation; officers worrying about how women would perform in the military; subway riders concerned that installing elevators for wheelchair users would increase their fare, and much more.

If MCS became accepted, people could be asked to tone down their use of fragrances, which strikes at the core of American individualism. There were angry comments about that from some newspaper columnists (Williams 1996; Bovard 1996).

What little sympathy was left evaporated when the corporate public relations machine convinced the media and the medical community that MCS was simply an imagined illness (EI Wellspring 2023).

## **Infighting**

The people who are willing to “stand on the barricades” can be a feisty lot, no matter what the cause is. Personality conflicts have also been a problem among MCS activists.

In 1994 there was an attempt at creating a national MCS advocacy organization named the National Coalition for the Chemically Injured (NCCI). It immediately ran into a turf war. Two of the established organizations (HEAL and NCEHS) opposed it, and CIIN was asked to stay out of it (Wilson 2007). Deprived of resources and support, the NCCI soon died.

There has also been infighting about what MCS is and how to treat it. Some people are in the “it’s chronic forever camp” while others believe in cures and positive thinking, and thus find the “chronic” people too depressing and counterproductive (Wilson 2004). This predates the rise of the more recent “brain retraining” movement, which further polarized the two camps.

There have also been cases of clashing personalities, which have weakened the ability of the MCS community to accomplish anything (Locke 2008; Wilson 2004, 2007).

The Executive Director of CIIN, Cynthia Wilson, once wrote (Wilson 2004):

*I’ve long maintained that you could put 7 people with MCS around a table with a million dollars on it. The group could spend the money any way it wished so long as they came to a unanimous agreement. I honestly believe the money would never be in jeopardy of being spent.*

Of course, it is possible to have multiple groups working in different ways towards the same goal. The women’s liberation movement in the 1960s and 1970s had a traditional advocacy group (NOW) that was run by older women, who were not comfortable with marches and other public protests. Then there were a lot of independent groups around the country that did “radical” protests, which attracted the college-age women. But this hasn’t happened with the MCS cause.

## **Lack of allies**

In the early years of the LGBT+ campaign, there was no unity. The lesbian and gay people looked at each other with some suspicion, and even more so upon the rest. They started to cooperate in 1978 to defeat the California Proposition 6 which would ban gay and lesbian school teachers. Slowly, more groups came together and made the overall movement stronger.

Several disability groups similarly started working with each other in the late 1970s. Those wheelchair ramps and other features are a direct result of it.

The MCS campaign needs allies. Some of the California protests could not have been done without the help of allies who could go inside toxic buildings, such as the Hilton, to protest the anti-MCS speakers at a conference of allergists.

The people with electrical hypersensitivity (EHS) are obvious allies, especially since EHS is so common among people with severe MCS. Then there are people with sensory overreactivity, such as hyperacusis, photosensitivity, autoimmune diseases, autism, and more. People with chronic fatigue syndrome (CFS/ME) also have similar interests.

A problem within the American disability movement is that some groups have higher status, and they are afraid of mingling with lower-status groups (just as able-bodied Americans are). The higher-status groups include those with mobility issues, such as quadriplegics and users of prosthesis. At the bottom are those with serious mental disabilities. It's a cruel hierarchy.

MCS is very close to the bottom, as it is widely believed to be a mental disease. It takes a microscope to distinguish the status-differences with CFS/ME and EHS, but they are there. CFS/ME is a little higher, and those folks seem not interested in associating with the MCS people. EHS is a little lower, and the MCS people tend to look down upon them (except in Sweden, where EHS is slightly "above" MCS).

It has multiple times been suggested to the MCS organization in Tucson, Arizona, that they "let in" the EHS people. Each time it was rejected, despite that many of their members have both MCS and EHS.

### **No new blood**

The people who were the leaders in the 1980s and 1990s are now aging, and they are not replaced by younger people. As a result, the three long-lived organizations HEAL, CIIN, and NCEHS have all become inactive.

The same is threatening the MCS and EHS organizations in Australia and Scandinavia, perhaps other countries as well.

In his classic book *Bowling Alone*, social scientist Robert Putnam found that Americans' participation in civic groups of all kinds peaked in the 1970s and has steadily retreated ever since. He blames it on several factors, with the by-far biggest being television. More recently, social media has become the big pacifier, especially among the younger people.

Television and social media teaches people to be inactive. Online petitions give the false sense of “doing something,” even though they are largely worthless. Politicians know how little effort it takes to click on an online petition. They only respect a real show of commitment to an issue, such as composing a personal letter or showing up in person to protest something. As always, it is the effort that counts.

This writer was once in the room when staff briefed a local politician about a protest. His first question was: “How many people showed up?”

### **More information**

More articles about the history, activism, and much else about the MCS community on [www.eiwellspring.org](http://www.eiwellspring.org)

### **Sources**

This writer has been involved in four different protest or advocacy movements. Three of them were related to environmental illness issues, one was totally unrelated.

The 1983 book *Social Movements of the Sixties and Seventies*, edited by Jo Freeman, and Judith Heumann's autobiography *Being Heumann*, provided much insight into what makes movements successful, which has informed this entire article.

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